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Progress in Standardization of Reporting and Analysis of Data from Early Hearing Detection and Intervention (EHDI) Programs

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Abstract

Congenital hearing loss affects one to three of every 1,000 live born infants. If left undetected, it may negatively impact children through delayed speech and language development. To help avoid developmental delays and ensure that deaf or hard of hearing (DHH) infants are identified and receiving services as early as possible, complete and accurate data are crucial. Despite substantial progress made over the years, some children are still delayed in identification and/or lost to the early hearing detection and intervention (EHDI) surveillance and tracking systems. Lack of standardization in data reporting contributes to this issue. This article discusses reasons for lack of standardization in data reporting and gives suggestions for how the situation could be improved.

Introduction/Background

Implementation of routine newborn hearing screening, known as universal newborn hearing screening, has provided the opportunity for infants who are deaf or hard of hearing (DHH) to be identified shortly after birth, and as a result, the age of identification for most babies in the United States has decreased from 2½ years to 2–3 months of age (White, Forsman, Eichwald, & Munoz, 2010). When late identified and therefore delayed in opportunities to acquire language and communication skills, these children will likely fall behind their hearing peers in communication, cognition, reading, and social-emotional development (Pimperton & Kennedy, 2012). With the widespread implementation of early hearing detection and intervention (EHDI) programs across the United States, more than 95% of newborns now receive a hearing screening, usually before hospital discharge (Centers for Disease Control and Prevention [CDC], 2016a).

However, providing a hearing screening is only the first step in the process for infants who do not pass the screening. To maximize the benefits of screening and to ensure early identification, it is essential that infants who do not pass the screening receive timely follow-

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up testing to confirm their hearing status. Infants diagnosed as DHH should receive early intervention services that meet the needs and preferences of the child and family. Timing from screening to enrollment into early intervention is crucial, so the Joint Committee on Infant Hearing (JCIH) recommends: (a) hearing screening no later than one month of age; (b) a diagnostic evaluation before three months of age for those who did not pass the newborn hearing screening; and (c) enrollment into early intervention services before six months of age for those who are diagnosed with hearing loss (JCIH, 2007). These recommendations are commonly referred to as the 1-3-6 benchmarks.

To ensure that DHH infants are receiving timely services, complete and accurate data reporting from hospitals, audiologists, and other providers to the state or territorial EHDI program[1] is crucial (Mason, Gaffney, Greene, & Gross, 2008). To help assess progress toward the 1-3-6 benchmarks the CDC EHDI program developed the Hearing Screening and Follow-up Survey (HSFS). This voluntary survey is completed by EHDI program staff and was designed in collaboration with partners that included Directors of Speech and Hearing Programs in State Health and Welfare Agencies, the Health Resources and Services Administration, and other stakeholders. The survey gathers non-estimated data related to the receipt of hearing screening, diagnostic testing, and enrollment into early intervention for all occurrent births within a jurisdiction in a given year.

In addition to monitoring progress toward the 1-3-6 benchmarks, the HSFS also allows the CDC to monitor progress in other areas, such as the number of infants not receiving or not documented to have received recommended follow-up services. These infants are referred to as being lost to follow-up or lost to documentation (LFU/LTD). Information gathered through the HSFS also allows CDC to collaborate and provide technical assistance to EHDI programs that need assistance. Since 2005, jurisdictions have been asked to complete and submit the survey annually and because the survey is voluntary, the response rate varies from year to year. For the year 2014, 57 of 59 (97%) jurisdictions completed the HSFS. Despite the significant progress in screening rates made over the years and improved efforts of public health programs and health care providers to ensure that all infants and children receive their recommended follow-up services, the LFU/LTD rate is still high in some jurisdictions and some children still fall through the cracks and are lost to the EHDI tracking and surveillance systems.

Reasons for Lack of Standardization in EHDI

Lack of standardization in reporting data regarding screening and diagnostic follow-up testing has contributed to some infants becoming LFU/LTD. Nationally, it is difficult to monitor children needing follow-up services and to accurately assess progress toward the 1-3-6 benchmarks when local data are incomplete and/or inconsistent. JCIH recognized the need for standardization of data definitions and reporting practices and their 2007 position statement noted that standardized reporting is crucial and that all federal and state agencies should standardize data definitions for higher quality and more reliable data (JCIH, 2007).

[1]Throughout the remainder of this article, “jurisdiction“ will be use to refer to states, territories, and other political jurisdictions that operate screening programs such as Washington, D.C., Puerto Rico, the Virgin Islands, etc.

Three primary reasons contribute to the lack of standardized data for EHDI programs across the nation. First, there are variations in the degree of completeness of data that jurisdictions report each year, which impacts national estimates. This is illustrated in Table 1 where a hypothetical country X is comprised of three jurisdictions: A, B, and C. Theoretically, the most accurate percentage of children with a confirmed hearing loss enrolled in early intervention (EI) is 67.2%, which includes all three jurisdictions (Equation 1). However, if Jurisdiction A did not report early intervention data, the percentage of children enrolled in EI would be reduced from the accurate 67.2% to 59.7% (Equation 2). When a jurisdiction is not able to report information on enrollment in EI or other data items, it impacts the representativeness of the national estimates. This could be due to the EHDI program not being linked with the EI program, which can occur when there is no data sharing agreement in place or the privacy laws within the jurisdiction disallow it. It could also be due to limitations with the functionality of the jurisdiction's EHDI Information System (EHDI-IS) that affects their ability to report all data. Limitations occur because although every jurisdiction currently has an EHDI-IS, the design and capabilities of these systems range from basic to advanced, impacting what can be reported. It is also possible that the jurisdiction is directed to only report certain data.

Second, despite substantial progress made in development and use of the EHDI-IS, challenges remain in ensuring complete documentation of services for the entire newborn population. This makes it difficult to ensure all infants are receiving recommended services and to generate accurate national estimates. Currently, screening results are consistently reported to the jurisdictional EHDI programs; however, the same does not apply to diagnostic test results and enrollment in EI. Reporting of EHDI data is not mandated by law in some jurisdictions. Infants who are referred for diagnostic evaluation and/or EI but did not receive recommended diagnostic and/or intervention services are commonly classified as LFU. Situations where an infant received the recommended diagnostic evaluation and/or intervention, but was never reported to the EHDI program, are referred to as LTD. Because it is difficult for EHDI programs to differentiate between infants who are LFU and those who are LTD, terms are typically used together. Table 2, which focuses on the screening stage, illustrates how a lack of documentation affects national estimates, using a hypothetical cohort of 100,000 births. Theoretically, the true overall screening rate is 95.6% (Equation 3), which includes all children who were screened, both documented and undocumented. However, the reported screening rate would be 86.1% (Equation 4), which is based on only those infants with a documented screen. This is an underestimate in comparison to the correct 95.6%. In addition, 11.7% of infants are LFU/LTD (Equation 5). Because of LTD, any reported LFU/LTD rate may not necessarily reflect the true burden of LFU/LTD. Time and resources could be unnecessarily expended on tracking those LFU/LTD children who already received services, subsequently reducing the efficiency of the jurisdictional EHDI program. Missing data is also a problem for infants who do not pass the hearing screening but are later found to have a normal hearing because they artificially inflate the estimated rate of hearing loss among infants who did not pass the screening.

Third, jurisdictions may define and calculate LFU/LTD in different, non-standardized ways. Despite formulas being provided and multiple instructional sessions about how to use the specified formulas, not all jurisdictions follow the guidance for the HSFS. The CDC defines

LFU/LTD on the HSFS based on infants who are referred for follow-up but are not documented as having received it for one of the following three specific reasons: (a) unable to contact the family, (b) the family was contacted but unresponsive, or (c) reason unknown. Reasons such as the infant deceased, the family moved, the parents declined, or the physician did not refer the infant, are not counted in LFU/LTD because the status of these infants is known to the EHDI program. The percentage of infants who are LFU/LTD for diagnostics is calculated by taking the number of infants LFU/LTD for diagnostics divided by the total number of infants not passing screening, then multiplying by 100%. The percentage LFU/LTD for early intervention is calculated by taking the number of infants LFU/LTD for EI divided by the total number of infants confirmed to have a permanent hearing loss, then multiplying by 100%. Table 3 reflects variation in calculating LFU/LTD for diagnosis, using a hypothetical cohort of 800 infants who did not pass the hearing screening and needed a diagnostic evaluation. For this scenario, according to the CDC guidance, the LFU/LTD for diagnosis would be 39.1% (Equation 6). Jurisdiction A, however, may calculate and report LFU/LTD differently in their reports and include all reasons except infant death, arriving at 48.1% (Equation 7). In contrast, Jurisdiction B may exclude from the LFU/LTD category infants whose families were unresponsive. This would bring their LFU/LTD estimate to 2.3% (Equation 8), an underestimate in comparison to the CDC's recommended formula of 39.1%. As can be seen, adopting definitions not in accordance to the HSFS guidance contributes to lack of standardization.

Lack of standardization occurs for many reasons. It can occur due to data programming within the EHDI-IS that collects and stores information in varying degrees of detail and granularity. It can occur at the local hospital/provider level with differences in what information is reported. It can occur at the jurisdictional level if EHDI programs calculate rates differently. And it can occur at the national level when jurisdictions change how they classify and/or report data in different years. Consequently, it is difficult to estimate the true number of children who are DHH and are not receiving follow-up services and to compare the data across jurisdictions and years. In response, the CDC and its partners have made a number of efforts to address this issue.

What has been done to address lack of standardization?

To help increase the standardization of data the CDC has made several updates to the HSFS since its inception based on feedback from jurisdictions and analyses of the reported data. One example is the updating of the definition for "In Process" for diagnostic evaluation, which has been revised twice to allow for more accurate reporting on the HSFS. In Process can occur when additional testing is needed to make a definitive diagnosis for an infant that did not pass the hearing screening. The revisions in the definition were made due to a higher than expected number of infants being reported in this category. The initial definition referred to infants that did not pass a hearing screening and did not yet have a confirmed diagnosis. In 2007, the definition was narrowed to specify that the infants reported in this category must have been seen by an audiologist for diagnostic evaluation at least once. If the infant was diagnosed as having a permanent hearing loss, it was to be reported as a "confirmed hearing loss," even if the degree of hearing loss (e.g., moderate or severe) was still undetermined. The definition clarified that scheduling an appointment for an initial

evaluation or only making a referral to an audiologist was not considered as In Process. In 2009, the definition was further refined and required that infants reported in this category not only must have been seen by an audiologist for diagnostic evaluation at least once, but also must have a follow-up appointment already scheduled. The change in definition has improved the accuracy of this data and the percent of infants reported as In Process has decreased from 16.0% in 2006 to 1.8% in 2013.

As another example, in 2015 the CDC collaborated with the EHDI Data Committee, which includes representatives from jurisdictional EHDI programs, the National Center for Hearing Assessment and Management, and other stakeholders to revise the HSFS's "Unresponsive" definition. Unresponsive is one of the three categories used by the CDC to calculate rates of LFU/LTD for diagnosis and intervention. The previous definition, "Parents or family of an infant who did not pass the screening were contacted but there was no documented response" was considered broad and contributed to a lack of standardization in data reported in the HSFS. The revised definition specified that for a case to be identified as "Unresponsive" the EHDI program or healthcare provider must have a documented two-way conversation or written communication with the child's legal parent or guardian in which the parent or guardian acknowledged awareness of the corresponding 1-3-6 recommendation and had nevertheless not obtained the recommended service. The revised definition has been used starting with the 2014 birth cohort survey and will make it possible to more accurately assess the number of infants that did not receive recommended follow-up services due to the child's parent or guardian being unresponsive. Going forward, it will be possible to either include these infants as part of the overall rate of LFU/LTD or to consider them separately.

In 2015, the CDC convened the EHDI Functional Standard Working Group, which included EHDI program staff from several states, and created the EHDI-IS) Functional Standards (CDC, 2016b). These standards provide jurisdictions with guidance on the technical and functional requirements for a complete EHDI-IS and are intended to identify the operational, programmatic, and technical criteria that all jurisdictional EHDI programs should implement when developing, using, and evaluating an EHDI-IS. The Functional Standards also define a set of data items that are considered to be essential for the EHDI tracking and surveillance process and aims to set the standard for minimum data collection at the jurisdictional level. Having an EHDI-IS that meets these requirements will better enable jurisdictions to collect, use, and provide complete and accurate data.

In addition to the above mentioned efforts to address the lack of standardization, the CDC has supported national standardization initiatives to improve interoperability between clinical electronic health records and public health information systems. Interoperability describes the extent to which systems and devices can exchange data and interpret that shared data. Within health care it refers to the ability for systems to work together and exchange information within and across organizational boundaries to advance the delivery of health care services. CDC EHDI is working to leverage advances in health information technology to ensure infants receive recommended services and improve standardization by helping connect public health and clinical services. As part of this effort the CDC is: (a) establishing national standards on information exchange and electronic quality measures (eMeasures), (b) promoting the use of standards to support data exchange with electronic

health records, and (c) developing standards-based tools to support clinical care coordination to help ensure infants receive recommended follow-up services. These standards and tools are designed to improve how data are collected, analyzed, and used, as well as strengthening service coordination between public health and early intervention providers.

To better utilize the surveillance data and to assess the performance of the EHDI process in a standard manner, CDC has developed three EHDI-related quality measures that were re-endorsed in 2015 by the National Quality Forum (NQF): Hearing screening prior to hospital discharge (NQF#1354), diagnostic evaluation no later than 3 months of age (NQF#1360), and signed Part C Individual Family Service Plan before 6 months of age (NQF#1361). The NQF is a not-for-profit, nonpartisan, membership-based organization that works to make improvements in health care by setting standards, recommending measures for public programs, identifying and accelerating quality improvement, advancing electronic measurement, and providing information and tools to aid health care workers in decision-making. An NQF endorsement reflects scientific, evidence-based review, patient and family input, and the perspectives of the health care industry.

The EHDI quality measures have been well received and adopted by a number of healthcare organizations. For example, the Joint Commission (formerly the Joint Commission on Accreditation of Healthcare Organizations) -- the nation's oldest and largest standards-setting accrediting body in healthcare -- has adopted NQF1354 "*Hearing Screening Prior to Hospital Discharge*" for their 2016 data reporting. Any accredited hospital may choose this measure set as one of their six required sets to satisfy their accreditation requirements. Similarly, an eMeasure version of this same measure is included as one of the 29 hospital measures in the 2017 reporting period for Stage 2 of the Centers for Medicare & Medicaid Services (CMS) Meaningful Use Incentive Program. NQF 1360 (audiology evaluation no later than 3 months of age), was recently included in the CMS's 2016 Core Set of Children's Health Care Quality Measures (Child Core Set). Implementation of a standardized Child Core Set is helping the CMS and states move toward a national system for quality measurement, reporting, and improvement.

To help jurisdictions understand these standards and measures, the CDC regularly holds webinars and meetings to educate and discuss with EHDI program staff ideas about how to improve reporting and documentation. Members of the EHDI Data Committee hold monthly conference calls to discuss methods to report more standardized data and to further improve quality. CDC EHDI staff members also participated in the standard development committee meetings and have recorded educational webinars on the interoperability standards that have been developed.

Conclusion/Next Steps

Lack of standardization for EHDI data occurs for several reasons and adversely affects the quality and accuracy of data. This makes it difficult to capture the true number of infants who are DHH and in need of services and to accurately assess progress toward the 1-3-6 benchmarks. It also makes it difficult to evaluate an EHDI program's effectiveness and overall success. The consistent availability of standardized data will better enable EHDI

programs to ensure that all infants who are DHH are identified early and receive the services they need in a timely manner. However, improving and maintaining data standardization requires continuous commitment and collaboration around the collection and reporting of complete and accurate data among jurisdictional EHDI programs, providers, the CDC, and other stakeholders. This can be accomplished by increasing awareness of the need for data standardization and improved reporting practices. Generating and assessing the data in a timely manner will also support this ongoing progress. The CDC EHDI program will continue to collaborate with and provide technical assistance to jurisdictional EHDI programs to strengthen their EHDI-IS, which will in turn expand capacity to collect and report complete and accurate data. Other efforts include updating and promoting the use of national standards on information exchange and electronic quality measures and supporting research to study the impact of complete and accurate data on the success of EHDI programs.

Acronyms

CDC	Centers for Disease Control and Prevention
CMS	Centers for Medicare & Medicaid Services
DHH	deaf or hard of hearing
EHDI	early hearing detection and intervention
EHDI-IS	EHDI Information System
EI	early intervention
HSFS	Hearing Screening and Follow-up Survey
JCIH	Joint Committee on Infant Hearing
LFU/LTD	lost to follow-up or lost to documentation
NQF	National Quality Forum

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Table 1

Effect of Lack of Standardization in Reporting on National Estimates

	Screening	Diagnostics		Early Intervention
Jurisdiction	**Not Pass Screen**	**Diagnosed**	**Hearing Loss Confirmed**	**Enrolled**
A	1,625	750	225	167
B	2,364	1,911	145	83
C	3,404	2,328	66	43
Total	7,393	4,989	436	293
Correct percentage of children enrolled in EI		67.2% or 293/436		(Equation 1)
Reported percentage of children enrolled in EI		59.7% or (83 + 43)/(145 + 66)		(Equation 2)

Note. EI = Early Intervention.

Table 2

Effect of Documentation Status on Data

Actual Screening status		**N**	**%**
Screening documented	Completed screening	86,126	85.1
	Incomplete screening	2,154	10.3
Screening not documented	Screening did in fact occur (LTD)	9,512	1.3
	Screening did not in fact occur (LFU)	2,208	3.3
Total		100,000	
Total percentage of children screened	95.6% or (86,126 + 9,512)/100,000		(Equation 3)
Percentage of children with complete and documented screens	86.1% or 86,126/100,000		(Equation 4)
Percentage of undocumented children (LFU/LTD)	11.7% or (9,512 + 2,208)/100,000		(Equation 5)

Note. LFU/LTD = lost to follow-up/lost to documentation.

Table 3

Adopting Different Definitions of Lost to Follow Up/Loss to Documentation Total Not Pass = 800

	N	
In process	5	
Non-resident	29	
Moved out of jurisdiction	15	
Medical reason	0	
Physician did not refer	1	
Infant died	8	
Parents / family declined	22	
Parents contacted but unresponsive	295	
Unable to contact	4	
Unknown	14	
Percentage of LFU/LTD, according to the CDC	39.1% or (295 + 4 + 14)/800	(Equation 6)
Percentage of LFU/LTD, according to Jurisdiction A	48.1% or (5 + 29 + 15 + 0 + 1 + 22 + 295 + 4 + 14)/800	(Equation 7)
Percentage of LFU/LTD, according to Jurisdiction B	2.3% or (4 + 14)/800	(Equation 8)

Note. LFU/LTD = lost to follow-up/lost to documentation; CDC = Centers for Disease Control and Prevention.